

“I need to talk to you,” said Abby Pearson as she stopped Steven Smith, her state representative, as he tried to rush through the capitol hallway to another meeting. She and her dad, Jeff Pearson, both residents of Plymouth Minnesota, got five minutes of the legislator’s busy day to listen to their concerns. She later spoke with State Senator Gen Olson at a town hall meeting. At both encounters, Abby wanted answers to some tough questions: “Can we get housing faster for individuals with disabilities?” “Can we get jobs for special needs kids, people who will pay taxes when they get a job?”

Abby’s disability is epilepsy, which in her case was the result of a birth trauma. She requires medication and regular naps to fight her exhaustion.

Along with her father, Jeff Pearson, Abby is a graduate of a nine-month long self-advocacy training program, Partners in Policymaking®, often referred to as “Partners.” A past chair of the sponsoring organization, the Minnesota Governor’s Council on Developmental Disabilities, Pearson wanted to experience the program that has been central to the Council’s goals over the past 25 years. Abby, 22, started Partners while she was completing her last year of the Transition program with Intermediate School District 287 in the northwest metro.

“I wish we would have done it earlier,” said Jeff Pearson, referring to the Partners training. He valued the tips on how to handle the Individual Education Program, or IEP, that was written and discussed between the parents, student and educators to guide her education for each year, from pre-school to graduation.

With the training Pearson reflected that “we would have had more confidence in knowing that it was our right.” He talked about the basic right of individuals with disabilities to have free and appropriate education. Although Pearson mentioned that IEP classes through Arc Minnesota were helpful, the best tips on getting the best educational plan came from other parents. Jeff’s wife, Ellen Pearson, recalled that even as educated professionals, she and her husband were still intimidated by school personnel early in Abby’s school life and failed to speak up when they had concerns about Abby’s training plans.

What would they have requested to guide Abby's education? Ellen Pearson said that their demands would have not been outrageous. They did request a quiet place for Abby to rest during the day since one aspect of her disability is her lack of stamina. They also asked that a paraprofessional accompany her during the school day. Both requests were denied. Their request for more computer time, an activity of high interest to Abby, was also denied.

The Partners program taught the Pearsons that the school cannot simply say, 'We don't have the money.' Even when the family offered several times to the elementary school to pay for their board certified behavioral analyst to meet with Abby's teachers so that they could better understand how to work with Abby and guide her behaviors, the school refused. Finally, when the school agreed to work with the professional, a different side of Abby was revealed. Now, the behavioral expert is being called in by the school to help other students.

Only after Abby ran out of the school building did the Pearsons come to believe that the school principal did not value special needs students. Following an appeal to the Superintendent, they determined that moving to another school was the answer, but regret that so many years were lost in Abby's education.

Speaking of the Partner's program, Jeff was surprised at the quality of the speakers and the large amount of resource materials that were provided. "Some were real 'preachers' and others were more calm but in five minutes you knew that they were real experts in their field and they had everyone's undivided attention."

Unsure that Abby would finish the class or find it "too hard," it was a surprise to her dad that she stayed engaged in each session and became fast friends with others her age, self advocates that she came to admire. Both are very proud that they were on time for every session.

Between each monthly seminar, online learning was required. Each subject covered by an expert speaker was covered in depth. After completing the online sessions, Jeff modified the training for Abby. Topics included the history of disabilities and the self-advocacy movement, education, housing and understanding the legislative process. Self advocacy skills, partnership building and community leadership were also covered.

While she is now living at home, Abby has a goal of moving into a group home or being in an apartment with a roommate in the Plymouth area. She would also like to learn to drive a car and be employed. She graduated from the Vector transition program in the Independent School District 287 serving the western suburbs and is currently enrolled in eQuality, a day training program that finds work experiences for individuals with disabilities.

The Minnesota Partners in Policymaking program runs from September to May, with monthly sessions starting on Friday afternoons and running through Saturday. The forty candidates selected are Minnesota residents who are parents of young children with developmental disabilities or individuals with disabilities. The goal is that the individuals become leaders in their own communities to advocate for individuals with disabilities. In addition to the history of disabilities, classes cover federal and state laws regarding benefits and support services for those with developmental disabilities and instruction on how to be a good advocate.

As a six year member of the Council, Jeff Pearson had always been aware of the high priority given the Partners in Policymaking program, which has graduated more than 800 people over the past 25 years. The work of the Minnesota Governor's Council on Developmental Disabilities is funded primarily by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities.

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